Making Visible the Invisible:
Using Photovoice to Understand Living with Brain Injury

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Abstract. Rehabilitation professionals have advocated for gaining an insider or patient perspective on living with disability, including brain injury, and facilitators and barriers to rehabilitation (Prigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al, 2000) and provide an opportunity for those with a chronic condition to play a participant-expert role in the research process (Booth & Booth, 2003; Bruyere, 1993; Balcazar et al, 1998). Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the combining of science and social practice (Adelman, 1993). For this study, carried out from September-November 2006, members of the 'Amazing' Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project (Wang, 1996), supported by BIA-MA and SHIP. The participating survivors took photographs of living with their brain injury, discussed them in a group, wrote narratives to accompany selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Grouped under nine categories, including Chaos, Strategies, and Hope for the Future, the images and narratives convey these survivors' challenges and sense of mutual support as they work to accept their different abilities and move on with their lives.

Research Objective. To gain an understanding of lived experience with brain injury and the issues, concerns, and strengths of brain injury survivors living in the community, while providing an opportunity for survivors to reflect on their lives, use their brains, and employ a variety of cognitive skills.

Sample. The participants are members of the 'Amazing' Brain Injury Survivor Support Group, which meets twice a month at the Metrowest Wellness Center in Framingham, MA. Eight members volunteered to participate in the study. All are long-term survivors, having received their injuries between three and 31 years prior to the start of the project. Six are traumatic brain injury survivors, one had a malignant brain tumor, and another had a non-malignant brain tumor with co-occurring stroke.

Study Design. This was a participatory action research study using photovoice, a type of action research in which people represent their lives, points of view, and experience using photographs and narratives (Wang et al, 1996). Action research in the tradition of Kurt Lewin involves integrating science and social practice in a dynamic group setting (Adelman, 1993). The first author, a doctoral student with extensive photovoice experience, co-facilitated this project with her two co-authors: the support group founder and a group member with photovoice experience.

The photography and discussion phase lasted 10 weeks, from September to November 2006. Using disposable cameras with 27 exposures, the participants took photographs of living with brain injury from their perspective and discussed them together as a group. They wrote narratives for images that they selected for exhibit, and grouped their photographs and narratives into nine categories. They held a trial exhibit and reflected on their experience with this project. The group initiated an outreach phase in January 2007, and their efforts are ongoing.

Principle Findings. Taking photographs triggered participant reflection on their situation and what they wanted to convey to others about living with brain injury. Talking about their photographs with the group prompted deep discussions of emotional (and other) issues that had not surfaced during regular support group meetings. The participants' images and narratives convey their challenges and sense of mutual support as they work to accept their different abilities and move on with their lives. Study data indicate that from the perspective of these survivors, healing from brain injury is a gradual process that continues for years.

Conclusions. This research project provided the participating brain injury survivors an opportunity to play a participant-expert role in the research process (Balcazar et al, 1998; Bruyere, 1993). The outreach phase is providing new opportunities to use prior experience with communication, layout, and group dynamic skills in a supportive environment. Participating in this study became a meaningful experience for participants and facilitators alike.

Implications for Policy and Practice. Rehabilitation professionals have long advocated for gaining an insider or patient perspective on living with disability, including brain injury (Prigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al, 2000).

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The Journey

It's a muddy, rutty, hands-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not and will not end....Sometimes weekly, and sometimes daily there is a new step to attempt to get to your "new self". You can't even ever hope to get back to your "old self". Oh well! Maybe there will be a good view on this journey that I hadn't expected.....

Lost Dreams

…this picture symbolizes what living with brain injury can be like....On an overcast day…I gazed up at the sky and took this picture through a tube. …In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear…

Chaos

I feel chaos. I leave the dishes to be done later. I procrastinate…I make no time for completing my tasks…I watch cable television or daydream so I don't have to deal with what I should be doing. This is the piano that I should and would love to learn how to play. I must practice.

Challenges

…Imagine yourself trying to run on ice…The faster you run, the more you get nowhere. These images parallel how each and every day of my life begins since I suffered my brain injury. I seem to spend a whole lot of time getting nothing accomplished.

Strategies

To compensate for my poor memory and organizational skills, I need to put labels on everything in my home. Where are my socks? Which of these is my schedule book? On which shelf did I put my Bible? These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.

My Advocacy Story

These are my counselors at Metro West Independent Living Center. They helped me to focus by bringing me to the statehouse to talk to my Senator and Representative.

Comfort and Support

With TBI certain parts of my life have added much comfort and support. God has blessed me with Teddy and Betty Marie. They welcome me home with hugs and slurps, we eat together, they sleep beside me and muzzle their noses into my neck and face to gently wake me in the morning. They delight me with their personalities and antics. They warm my heart and comfort me. They make me smile and laugh. God has Blessed me with a little glimpse of heaven.

Acceptance

Whose grave is this? Surely it's not mine. This is not my fate, it is? I need to make the best of this situation, but how? It's all suddenly complicated...This was not my doing, nor my choice! I'm trying to be gracious. I need to accept this death of my "old self".

Hope for the Future

New Identity. New passion of gardening. First baby step was planting in containers so as to not fall into dirt because of imbalance. My garden has progressed as my new life has. Now I not only can plant in the ground, I dig up grass and now have three perennial gardens.